erly interpret the information as it applies to their condition. Second, it may bring home the message that it is impossible to keep up with all of the latest in medicine. This realization may force us to frequently re-educate ourselves in response to patients' questions. The challenge to health care providers is to become as facile with the web as are our patients and to embrace it as a source of medical education. Services such as MD-Consult (www.mdconsult.com) provide almost instantaneous access to the full text of peer-reviewed journals and textbooks. There is no longer any need to make onerous and time-consuming trips to the library.

There is also an implied dichotomy in these results. Patients get information from their physician or from the web. This separation is artificial. There is no reason that we cannot harness the World Wide Web so that patients can get information from their physician by this same vehicle. We can act as a guide for our patients to help them avoid misinformation. It is impractical for each of us to develop our own compendium of online information. It is not beyond us, however, to develop a home page for our practices with links to reputable information sources (for example, American Cancer Society, Mayo Clinic, etc.). You can pick and choose particular advice from each site until you have a complete portfolio of patient information. You can also refer your patients to sites that display the Health on the Net (HON) logo. The HON criteria, which can be found at www.hon.ch/HONcode/Conduct.html, are, among other things, a voluntary attempt to protect patient privacy, to assure that qualified professionals are providing online information, and to make readers aware of any biases that a site may have (for example, commercial support). These steps will help, but not entirely ensure, that the information your patient is accessing is credible.

Among the dilemmas raised by the World Wide Web is what constitutes a physician-patient relationship in a virtual environment? Does giving advice by e-mail to an individual who is not a patient in your practice constitute a legally binding physician-patient relationship? If it does constitute such a relationship, are you practicing medicine without a license if you give e-mail advice to a patient who lives out of state? If a site answers patient questions and is making money from advertising, does this form a contractual arrangement between the site and the patient? The legal implications will, I am sure, develop over time.

Experiences of hospital care and treatment-seeking behavior for pain from sickle cell disease: qualitative study

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Funding: The King's Fund and Marks and Spencer

Competing interests: None declared

This paper was originally published in the BMJ 1999;318:1585-1590.

ABSTRACT ● **Objective** To investigate how sociocultural factors influence the management of pain from sickle cell disease by comparing the experiences of those who usually manage their pain at home with the experiences of those who are more frequently admitted to hospital for management of their pain. ● **Design** Qualitative analysis of semistructured individual interviews and focus group discussions. ● **Participants** 57 participants with genotype SS or S/β-thal (44 participants) or SC (9 participants); the status of 4 participants was unknown. 40 participants took part in focus groups, 6 took part in both focus groups and interviews, and 9 were interviewed only. Participants were allocated to focus groups according to ethnic origin, sex, and the number of times that they had been admitted to the hospital for the management of painful crises during the previous year. ● **Results** The relation between patients with sickle cell disease and hospital services is one of several major, nonclinical dimensions that shape experiences of pain management and behavior for seeking health care. Participants' experiences of hospital care show a range of interrelated themes that are common to most participants across variables of sex, ethnicity, and which hospital was attended. Themes identified included the mistrust of patients with sickle cell disease, stigmatization, excessive control (including both overtreatment and undertreatment of pain) and neglect. Individuals responded to the challenge of negotiating care with various strategies. Patients with sickle cell disease who are frequently admitted to hospital may try to develop long-term relationships with their caregivers, become passive or aggressive in their interactions with health professionals, or regularly attend different hospitals. Those who usually manage their pain at home expressed a strong sense of responsibility for the management of their pain and advocated self-education, assertiveness, and resistance as strategies toward hospital services. ● **Conclusions** The organization and delivery of management for the pain of a sickle cell crisis discourages self-reliance and encourages hospital dependence. Models of care should recognize the chronic nature of sickle cell disorders and give priority to patients' involvement in their care.

INTRODUCTION

The management of sickle cell disorders is of growing concern for health professionals and policymakers in the United Kingdom. Painful crises are the dominant feature of sickle cell disorders both for the person who is suffering and for service use.[1] In the United States, most painful episodes are managed at home,[2,3] and many patients with sickle cell disease do not normally use health services to manage pain.[2] Analysis of patterns of treatment seeking in the United Kingdom is hindered by the lack of coordinated information about the affected population.[4] Ongoing analysis of data on hospital admissions and estimated population figures, however, suggests that there is a similar pattern of service use to that in the United States, with a small percentage of the affected population consuming a disproportionate amount of resources. Most previous research has systematically excluded individuals who have infrequent contact with hospitals, assuming that they experience little or no severe pain.[5] Those who manage their pain at home have been similarly neglected by the organization of health services, which has focused on acute management rather than on primary and community care. Published research tends to ignore both the experiences of individuals who manage their pain in the community and the influence of nonclinical factors on treatment-seeking behavior.

Biomedical approaches to pain have traditionally conceptualized the experience of pain as fundamentally individual and purely biological.[6] Our investigation draws on the anthropological understanding that sociocultural factors influence the perception of, response to, and communication of pain.[7] Similarly, treatment-seeking behavior is a social action influenced by social context and individual meanings and experience; it is not simply a straightforward individual response to the experience of physiological symptoms. We aimed to compare the experiences of pain and its management in patients with sickle cell disease who had different frequencies of hospital admissions and to identify nonclinical factors contributing to patterns of service use. Given the lack of research on this issue, we have used mainly qualitative methods to gain insight into the range of possible factors influencing experiences.[8]

PARTICIPANTS AND METHODS

We used focus group discussions and semistructured individual interviews as our main methods.

Participants

We recruited 57 participants with sickle cell disease (hemoglobin type SS or S/β-thal or SC) across the greater London area using theoretical sampling (systematic, nonrandom sampling of participants possessing specific characteristics selected to aid the development of theory) via a wide range of channels (Table 1).[9] The main study groups comprised participants admitted to the hospital with a painful crisis 3 or more times in the previous 12 months and those admitted once or not at all.

Ethical approval for the study was obtained from the research ethics committee of St Thomas's Hospital, London. All participants completed consent forms before participating in interviews or focus groups.

Structured questionnaire

All participants completed a short, structured questionnaire to collect sociodemographic data (Table 2) and information on hemoglobin status, usual analgesic drugs, and current treatment (Table 3); participants then took part in an interview or focus group or both. Participants were asked how often they were admitted to the hospital and about painful episodes. The definition of painful episodes was similar to that used in previous studies: "pain that was in any part of your body, lasted at least 2 hours, you felt was caused by sickle cell, and may or may not have led you to go to hospital."[10]

Interviews

We conducted 18 semistructured interviews with 15 persons in settings chosen by the participants. Six pilot interviews were conducted before the focus groups to develop the topic guide. Ten interviews were conducted in parallel with the focus groups with persons who spent significant time in the hospital and who were unable to attend a focus group.

Focus groups

Participants were allocated to 1 of 8 different focus groups on the basis of information provided in the questionnaires;

Table 1 *Channels of recruitment*

	Number (%) of hospital admissions per year	
	3 or more (n = 28)	1 or fewer (n = 29)
Researcher visiting inpatients	9 (32)	0
Referral by counselor or specialist nurse	8 (29)	9 (31)
Snowballing*	3 (11)	1 (3)
Participant in previous research	2 (7)	2 (7)
Researcher visiting outpatient clinic	6 (21)	11 (38)
Media	0	2 (7)
Mailing	0	2 (7)
Referral by general practitioner	0	2 (7)

*Recruitment of further participants by networks of those already participating.

Table 2 *Characteristics of participants*

	Number (%) of participants (n = 57)
Ethnic origin	
West African	29 (51)
Afro-Caribbean	26 (46)
Other African	2 (4)
Sex	
Female	32 (56)
Male	25 (44)
Age (years)	
20–40	49 (86)
41–60	6 (11)
Missing data	2 (4)
Mean age	34

the composition of each group was determined by ethnic origin (African-Caribbean or west African), sex, and the number of times participants had been admitted to the hospital in the previous year (>3, or <1). Each group met for two discussions of 1.5 to 2.5 hours. The main topics discussed in the focus groups were diagnosis, childhood and adult experiences of pain, hospital experiences, primary care, analgesia, the anatomy of a crisis, employment and education, support and relationships, and identity and lifestyle. All focus groups were facilitated by 1 of us (K. M.; the only nonparticipant present), whose role was to introduce the topics, ask questions, and encourage participation by all group members. The facilitator aimed to maintain a balance between covering the intended topics and allowing for the introduction of unanticipated issues that participants deemed relevant.

Statistical analysis

We analyzed the data from the quantitative questionnaire using statistical software (Epi-Info, Version 6; Centers for Disease Control and Prevention, Atlanta, GA). The qualitative data consisted of the transcripts of interviews and focus group discussions. All qualitative data were professionally transcribed; the main researcher then checked the transcripts against the original recordings for accuracy and the inclusion of nonverbal detail (such as laughter, murmured assent, etc). Owing to the large volume of data, one of us (A. S.) did not listen to the recordings or participate in coding but read all transcripts and discussed the evolving coding framework at regular intervals. We used another software program for the analysis of the qualitative data (Nud*ist, Version 4; Qualitative Solutions and Research, Victoria, Australia). Coding categories were developed from the data rather than using a predetermined analytical framework. Text units (each uninterrupted segment of speech) were grouped together according to perceived common underlying themes. As coding progressed, each of these general themes was further subdivided as a greater understanding of the complexities of the data developed. The identification of horizontal relations between coding categories was a parallel process eventually leading to the development of an explanatory model, an aspect of which is presented here.

Validation

At the end of the study, information on the results of laboratory electrophoresis was obtained for most patients and compared with participants' self-reported hemoglobin status. The researcher also validated the accuracy of participants' reported pattern of admissions in those for whom there was any doubt by discussion with hemoglobinopathy counselors and staff at outpatient clinics.

RESULTS

Questionnaire results

Twelve London hospitals were named by participants as their base hospital; two participants reported regular attendance at several hospitals. Patients admitted infrequently were less likely to use strong opioids and more likely to use mild analgesics in the hospital (Table 3). The proportion requiring strong analgesics was 100% for those admitted three or more times each year compared with 72% for those admitted fewer than three times (95% confidence interval for the difference in the proportions between groups: 10%-46%). There was considerable overlap in the number of painful episodes between those admitted frequently and those who usually managed their pain at home (Table 3): half of those who managed their pain at home had experienced 10 or more painful episodes during the previous 2 years. Of the 51 cases in which self-reported results were compared with laboratory results, there was agreement in all cases of SS or S/β-thal (40 cases) and SC (9 cases). Two (of a total of 4) cases in which participants did not report or did not know their hemoglobin status were identified as being SS (both of these were patients who managed their pain at home).

Qualitative results

We identified sociocultural and psychological factors that, along with differences in clinical severity, might contribute to variations in the pattern of hospital use by persons with sickle cell disorders. We focused on two main themes: experiences of hospital care and strategies for the management of pain and treatment seeking.

Experiences of hospital care

Our findings related to general aspects of the hospital experience that were consistent for most participants, although a few had little experience of hospital care.

Table 3 *Hemoglobin status and treatment in the hospital by number of hospital admissions per year*

Variable	Participants (n = 57)*	Hospital admissions per year 3 or more (n = 28)	1 or fewer (n = 29)
Hemoglobin status			
SS or S/β-thal	44 (77)	24 (42)	20 (35)
SC	9 (16)	4 (7)	5 (9)
Unknown	4 (7)	0	4 (7)
Transfusions and hydroxyurea			
Transfusion ever	43 (75)	19 (33)	24 (42)
Transfusion regimen currently	4 (7)	4 (7)	0
Using hydroxyurea	5 (9)	5 (9)	0
Missing data	5 (9)	0	5 (9)
Usual drugs taken in the hospital			
Strong analgesia (pethidine, diamorphine or morphine, or a combination)	45 (79)	27 (47)	18 (32)
Not strong analgesia (no pethidine, diamorphine or morphine, or a combination)	7 (12)	0 (0)	7 (12)
Missing data	5 (9)	1 (2)	4 (7)
Number of self-reported painful episodes in previous 2 years			
1–2	2 (4)	0	2 (4)
3–10	17 (30)	5 (9)	12 (21)
11–20	12 (21)	4 (7)	8 (14)
21–30	8 (14)	4 (7)	4 (7)
>30	13 (23)	11 (19)	2 (4)
Missing data	5 (9)	4 (7)	1 (2)

*Values are numbers (percentages). Painful episodes do not add up to 100% because of rounding.

Mistrust

Participants gave accounts of mistrust by their professional caregivers. In all of the groups who were frequently admitted to a hospital (groups 1-4) and two of the groups who managed their pain at home (groups 5-8), participants described being suspected by health professionals of exaggerating pain:

"The doctor will look at you, and he goes, 'I don't think that you're in a lot of pain' " (focus group 1).

In contrast, some participants managing their pain at home described how health professionals seemed to suspect them of understating their pain:

"They get suspicious because they can't believe you can be better in 2 days, but if I can look after myself, I don't see why I should be there . . . I feel better, I can stop taking [the painkillers] . . . Once I didn't have [any] more pain, but they [were] giving me tablets which I didn't know [were] painkillers" (focus group 7).

Stigmatization

The perception of patients with sickle cell disease that they were treated differently from other inpatients was a prominent theme in all focus groups and interviews. Virtually all participants thought that patients with sickle cell disease were stigmatized as drug addicts: a stereotype that simultaneously feeds on and reinforces the mistrust of patients with sickle cell disease described above.

"The nurse turned around to me and said, 'It's not because we don't [want to] give you the painkillers, it's [because] we're scared that you're [going to] get hooked on it, and we don't [want to] see you down on the street hustling drugs' " (focus group 3).

Control

The issue of control was closely related to mistrust and stigmatization. Participants described various ways in which health professionals routinely exerted control over their care regimens and failed to involve them in decision making, particularly in relation to giving drugs (overtreatment as well as undertreatment of pain), hospital admissions, and discharge.

Patient: "They give me diamorphine [diacetylmorphine hydrochloride], but I try to take as small [an amount] as I can . . . sometimes they push."

K.M.: "They want you to take more?"

Patient: "Yes. They keep saying to me, 'Oh, the pain will come again.' And I say, 'When the pain comes, I will tell you' " (focus group 7).

Patient 1: "You do tend to find certain nurses who like to overstep their bounds, they feel they know the best regime[n] for your painkillers."

Patient 2: "Absolutely."

Patient 1: "They feel that you should be having less than . . . on the prescription . . . and they will try and

control your pain regime[n] to the way they think it should go" (focus group 2).

"They kept saying, 'I think we're going to send you home,' and yet, I knew it was the sort of chest pain that I should be in. . . . So there was this debate . . . in the end, I was right: it was sickle lung" (focus group 5).

Neglect

Participants spoke of the neglect of a range of needs, including personal care and monitoring of vital signs. Some participants related such neglect to wider issues such as understaffing, whereas others interpreted it as further evidence that patients with sickle cell disease were a low priority for health professionals. Failure to provide adequate psychosocial support was also included as an example of neglect, although this is a major issue that we can refer to only briefly here.

"[The nurses] just seem to concentrate on the pethidine [meperidine hydrochloride] injections, and that's it. I've been in days without having any assistance with my hygiene and personal care and changing of the sheets and helping me with fluids . . . just basic stuff like that" (from an interview).

"On [names ward], observations wasn't done. . . . If they come around and you're asleep, then they leave you. . . . Sometimes they've already written in what your temperature is, but the thermometer is still under your arm" (from another interview).

"You need to talk about what's bothering you, but that is not an issue when you go in hospital: they see that you've got sickle cell, and that's it. . . . I went into a state where I was practically suicidal, and nobody recognized nothing except that I had sickle crisis" (focus group 1).

Strategies for pain management and treatment seeking

The extent to which a person's relation to pain had been shaped by these experiences was variable, and each person responded differently to the challenges of negotiating the management of pain and general care. Those who normally managed pain at home used different strategies from those who were frequently admitted to the hospital.

Strategies of patients managing pain at home

The strategies used by patients managing pain at home were typified by two main characteristics: a sophisticated critical appraisal of hospital services, which acknowledged that spending time in the hospital was often not in the patient's own best interest, and a strong sense of self-responsibility for the management of the condition, which included a recognition of the power of mental attitudes.

Assertiveness

"People think, 'Oh, the doctor knows best,' but I think the patient knows best, because, really, if you don't believe in yourself, no matter what the doctors do, it's not [going to] help you. You have to have that self-power to say, 'Look, enough's enough.' Because how long are you going to carry on taking all these different drugs? How long are you [going to] keep on dealing with the side effects?" (focus group 7).

Self-education

"I think you do have to educate yourself because you'll be in wards where nurses have never seen a sickler—it didn't come up in their training—so I think it really comes down to you at the end of the day" (focus group 6).

Resistance

"I'd work during the day . . . in agony, go home . . . take the pethidine [meperidine] through the night, get up the next morning, go to work again without taking any drugs—in pain, agony—come home in the evening and repeat the same thing again. So you're always trying to fight with it" (focus group 6).

"It's good to try and have a positive mind, not 'Oh, the pain's here. I'm gonna just let it take over me,' not lie down in [the] hospital for weeks on end, getting them to drug you up 'til God knows" (focus group 7).

"Sometimes you want to fight it, and you don't want to go into [the] hospital, because you know what [the] hospital is, and you know what staying out of [the] hospital can do, and you know whether you're going to be better within 2 or 3 days of staying at home, hopefully, or you may be in [the hospital] a week or 10 days. So it's all about mental toughness" (focus group 8).

Strategies of patients frequently admitted to the hospital

Participants who were more frequently admitted to the hospital advocated the benefits of developing long-term relationships with caregivers in 1 hospital to receive more individualized care. This strategy may be thwarted by the high turnover of nurses and interns; some participants emphasized the significance of their relationship with their consultant/specialist as a bulwark against mismanagement and the unsympathetic attitudes of junior staff. A minority of the patients who were admitted to the hospital frequently resorted to verbal and occasionally physical aggression, sometimes provoked by the undertreatment of pain and poor communication with health professionals and at other times as an expression of unresolved anger. Others reported that they maintained a passive attitude in their interactions with their caregivers, which necessarily extended to their attitude toward their condition. Discharging themselves from 1 hospital and going straight to another in response to unsatisfactory care was a strategy used by a minority of patients.

Developing relationships
"If you're in a regular hospital where they know you . . . they tend to be able to build up some form of relationship because they've seen you before. So they know exactly how your crisis behaves, how you usually cope. They can work with you" (focus group 1).

Aggression
"Every time I come to [emergency], he [the intern] will send me home . . . . One day, he canceled my painkiller and said I would have to go home, and I said, 'Today I'm not going home.'. . . So I held him, and I punched him" (interview).

Passivity
"Whenever they [doctors and nurses] say anything to me that I don't like, I just let it go by . . . . Whatever they want to do, they can just do it to me" (interview).

Use of multiple hospitals
"I've been in many hospitals [names 5; laughter from group] . . . . If I go to the hospital and my pain's not controlled, I don't care if I die, I'll get out of that hospital and go somewhere else to get pain free or to control my pain" (focus group 3).

DISCUSSION

In our study, we used methods that facilitated the emergence of participants' own accounts of their experiences, with minimal imposition of a predetermined analytical framework. Our findings suggest how a person's management of pain may be affected by experiences of, and responses to, health services. This comparative approach found that there were similar experiences of hospital care in London, across variables of sex, ethnicity, and hospital attended. We also highlighted striking differences in attitudes toward hospital services between those who usually manage their pain at home and those who are admitted to the hospital more frequently.

Our investigation has been innovative in including individuals with sickle cell disorders who had previously been excluded from research: those who usually manage their pain at home. The knowledge that some persons with sickle cell disorders rarely experience severe pain suggests that those managing their pain at home may fall into this category. In the absence of an objective measure of clinical severity, we have used the self-reported frequency of painful episodes to measure pain in participants who were admitted to the hospital infrequently. This imperfect indicator relies on subjective recall over a significant period. We think, however, that taken together with participants' accounts and the fact that many of those who usually managed their pain at home were known to counselors or attended outpatient clinics (Table 1), these data provide evidence that home management is not simply a reflection of lesser disease severity. Although the patients who were admitted to the hospital more frequently reported a greater overall number of painful episodes, there was sufficient overlap between the two groups to show that they are not two clinically discrete populations. In addition, the two groups seemed to have a similar distribution of genotypes. Validation of patients' self-reported hemoglobin status (when known by patients) showed that there was complete agreement with laboratory records, suggesting that accurate information was provided by the study participants.

Hospital experiences and management of pain: explanatory model

Our participants' accounts of hospital care accord with previous research in highlighting issues of stigmatization, a lack of involvement in treatment decisions, and undertreatment of pain.[11-13] Our findings suggest a model that illustrates the implications of the relationship between health professionals and patients for the individual's management of pain (Figure 1). A pervasive mistrust of patients with sickle cell disease leads health professionals to exert excessive control over their pain management regimen. Other studies have found that a significant proportion of health professionals may subscribe to the stereotype of patients with sickle cell disease as drug dependent.[14,15] The undertreatment of pain from sickle cell disease has

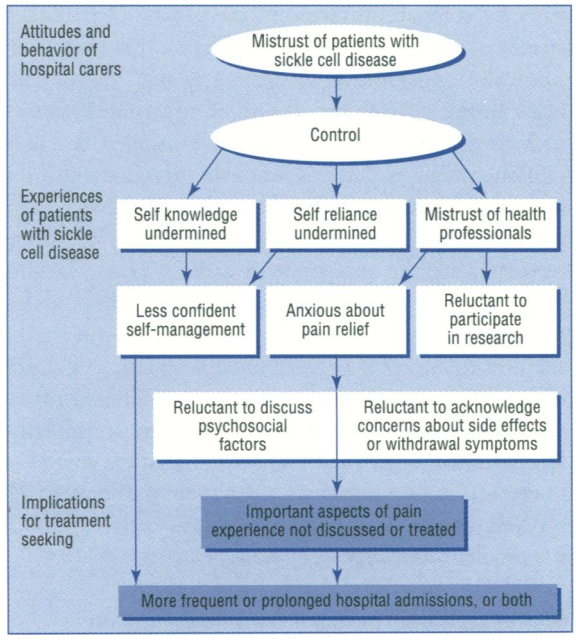

Figure 1 How hospital experiences may adversely influence individual pain management in patients with sickle cell disease

been described elsewhere[11-13]; our findings indicate that health professionals may also be overtreating pain, particularly in those patients who are only rarely admitted to the hospital. This observation suggests that the approach to treatment was not due solely to health professionals' concerns about addiction, but also related to more fundamental issues of trust, control, and the involvement of patients. Failure to involve patients with sickle cell disease in making decisions about their care undermines their self-reliance and self-knowledge, reducing their capacity for self-management.

Repeated experiences of control and neglect erode patients' trust in their professional caregivers, leading to considerable anxiety about receiving adequate pain relief. Ballas observed that "Patients with sickle cell disease often do not convey their true feelings about their management for fear of not receiving adequate treatment for pain."[16] Similarly, we found that patients may be reluctant to discuss certain issues, such as withdrawal symptoms and the influence of psychosocial factors on painful crises and hospital admissions, which they feared would diminish the validity of their entitlement to treatment in their caregivers' eyes. This mistrust of health professionals seems to have adversely influenced recruitment into research and clinical trials[17]; difficulties experienced in recruiting patients who were frequently admitted to the hospital for the current study were further evidence of this effect.

An understanding of the history of race relations in the United Kingdom prompts the question: to what extent do the experiences of mistrust and stigmatization of patients with sickle cell disease mirror the health care experiences of London's black population more generally? There is little basis for comparison owing to the paucity of published research on this issue, although alienation has been identified as a major theme in existing work.[18] In contrast, black British people's experiences of other public services such as education and policing have inspired far more published analyses, and it is reasonable to suppose that the health care experiences of black people might show parallel themes of institutional racism. Any degree of alienation characterizing the experience of a black person seeking treatment for a racially neutral condition is compounded in the case of a patient with sickle cell disease owing to the status of the disorder in the United Kingdom as a "black disease." This racialization may have contributed to the development of an inadequate policy response, underdevelopment of services and undercoverage of the condition in medical and nursing curricula (unpublished data).[19] All of these factors are probably significant determinants of the problems highlighted by our research.

Sickle cell disorder as a chronic condition

Recent models of chronic disease and disability emphasize the role of the social and political environments in perpetuating dependency.[20] Experiences of hospital care for pain from sickle cell disease may disempower patients, inhibit self-management, and actively contribute to dependence on acute care services, as our model illustrates. The implications become salient when this model is considered in the context of the underprovision of public services for sickle cell disorders: that is, the lack of primary and community care and the failure of policymakers in social services, education, and housing to acknowledge the special needs associated with this condition.[21,22] Thus, the path of least resistance leads to hospital dependency. Although our findings indicate that many of those affected have resisted this route, further work is needed to understand the factors contributing to such resistance; greater insight may also be achieved by comparison with other chronic conditions.

The status of sickle cell disease as a chronic disorder is inadequately recognized by policymakers and service providers. The management of chronic disease demands that health professionals and patients work in partnership,[23] whereas our findings indicate that pain management for sickle cell disease is based on the acute care model. Recent discussions about models of care for sickle cell disorders have frequently degenerated into arguments about the use of opioids for pain.[24,25] Commentators have failed to acknowledge either the complexity of the relationship between patients with sickle cell disease and health professionals or the attendant implications for the experiences of pain and treatment seeking. The use of principles of palliative care[26] and models of care for other chronic conditions[23,27] could enhance this discussion; of particular relevance are issues of communication, continuity of care and home care, intersectoral collaboration, and a holistic understanding of pain. Models of care for patients with sickle cell disorders should also be informed by the recognition of this population's diversity. The historical focus on the minority of the population with sickle cell disease who frequently use acute care services perpetuates both the stigmatization of service users by health professionals and bias in research and the organization of services.

We thank the individuals who took part in the research and the health professionals and others who assisted with recruitment, in particular: Marjorie Ferguson, Connie Harewood, Nadine Hay, Naheed Mir, Chioma Nwonkonkor, Comfort Okolo, Norman Parker, John Porter, Tom Pearson, Emma Prescott, Shirley Samuel, Beverly Smalling, Jenneh Soya-Bonga, Adrian Stevens, Nikki Thomas, Sharon Waller, Neill Westerdale, and Ann Yardumian. The study was overseen by a multidisciplinary steering group (including service user and voluntary sector representatives), whose members have provided expert assistance throughout the project. We also thank Nicola Low, Chris McKevitt, Rosie Denmark, and Graham Serjeant for useful comments and Ruth Dundas for assistance with statistical analysis.

Contributors: K.M. initiated the research, was involved in the study design, undertook data collection and analysis, and drafted the paper. A.S. was involved in the study conception and design and contributed to

data analysis and the paper. D.B. contributed to the study design, discussed emerging ideas, and contributed to the paper. A.S. and K.M. will act as guarantors for the paper.

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COMMENTARY
Don't blame the patients

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It is estimated that about 70, 000 Americans have sickle cell disease. In a given year, only about 50% of this group will have even one episode of pain. Only between 1% and 3% will have six or more painful episodes, and a minority of patients seem to have severe pain almost constantly.

It is the minority of sickle cell patients who have frequent episodes of pain or nearly continuous pain who repeatedly seek treatment for their pain at hospital emergency departments and inpatient wards. They are difficult patients: they do not really get better, they keep coming back with the same problems, they are demanding, and worst of all, they want narcotic analgesics, drugs that physicians are uncomfortable about dispensing.

Because they engender such discomfort in their caregivers, these patients are generally not treated well. There is little evidence to the contrary; the literature is replete with articles describing, from the patient's viewpoint, inadequate treatment of pain, hostility, and implicit or explicit accusations that drug addiction rather than "real pain" was their problem. The patients interviewed by Maxwell and colleagues confirm this information.

The clinical spectrum of disease in sickle cell patients ranges from those with severe symptomatic hemolytic anemia and frequent crises to those who would remain undiagnosed but for routine testing. Although it is clear that a spectrum exists in the objective manifestations of sickle cell disease, such as extreme variations in the severity of anemia, aseptic necrosis of bone, and renal disease, we are uncomfortable that such variations in a "subjective" symptom such as pain should also be attributed to the disease. Because there is no demonstrable reason why one patient should have more pain than another and no way to demonstrate objectively that a patient actually has pain, physicians trying to understand the situation resort to a strategy of "blaming the victim." The entire difficult, frustrating situation can be explained by deciding that the patient is an addict and the (otherwise inexplicable) behavior is not due to pain.